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Cultivating inclusivity in precision medicine research: disability, diversity, and cultural competence

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Abstract
Cultural competence is increasingly viewed as key for the inclusion of diverse populations in precision medicine research (PMR) in the USA. Precision medicine researchers and personnel are thus increasingly expected to undergo cultural competency trainings and to engage with relevant racial/ethnic communities to ensure that all research components are culturally and linguistically sensitive to these communities. However, the need for PMR enterprises to ensure competence with and under- standing of disability rights, history, and needs (hereinafter disability culture competency) have not received attention. This article discusses the importance of disability inclusivity in PMR and the construct—and challenges—of disability as a cultural com- munity. Reviewing and extrapolating from studies in healthcare settings, the article considers three interrelated issues that are likely to impact disability inclusivity in PMR: disability accessibility and accommodation; disability stigma and unconsious bias; and disability language and communication. Next, disability competency trainings that were developed in healthcare settings are surveyed and their applicability for PMR is discussed. The arguments advanced are that disability culture competency among precision medicine researchers, personnel, and oversight committees is essential to upholding the welfare and rights of human subjects with disabilities in PMR; that engagement with disability communities is imperative for this endeavor; and that such knowledge of disability culture is crucial for cultivating inclusivity of people with different (dis)abilities in PMR.

Keywords Disability · Precision medicine research · Health disparities · Cultural competence

Introduction

Cultural competence is increasingly viewed as a foundational pillar for cultivating inclusivity of diverse populations in pre- cision medicine research (PMR) (The Precision Medicine Initiative Working Group 2015). Several inter-related and ac- cumulative considerations have led to this development: the need to create racially/ethnically diverse cohorts that are suf- ficiently powered for meaningful scientific findings to emerge (Petrovski and Goldstein 2016; Cohn et al. 2016); the sizable non-white population in the USA that continues to be under- represented in genomic research (Popejoy and Fullerton 2016); the understanding that, while trust plays a key role in

decisions to participate in PMR, incidents of inequitable and unethical treatment (e.g., the Tuskegee Study of Untreated Syphilis In the Negro Male) have increased the distrust of communities of color in medical and research enterprises (Bentley et al. 2017); the recognition that research to improve health outcomes requires culturally sensitive research designs and collaboration with racial/ethnic communities (National Institutes of Health 2017); and the goal of PMR—as a new healthcare model that promotes prevention and treatment based on individual genetics, environments, and lifestyles— to reduce existing health disparities that are alarmingly high among communities of color.

Cultural competency trainings are believed to facilitate these issues. Introduced in the 1980s in healthcare settings, and promulgated in federal and state regulations (National Institutes of Health 2017), such trainings have obtained prom- inence as an invaluable approach to improving healthcare pro- vision to racial/ethnic groups and reducing health disparities (Truong et al. 2014). Indeed, although there is variation in the content and approaches to cross-cultural health education (Kripalani et al. 2006), cultural competency trainings are be- lieved to increase professionals' knowledge of diverse health

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cultures and to encourage self-critique, by emphasizing attentive listening, and awareness to unconscious biases that may impact health provision (so-called cultural humility) (Isaacson 2014).

The Liaison Committee on Medical Education (LCME), for instance, requires accredited medical programs to "ensure that the medical curriculum provides opportunities for medical students to learn to recognize and appropriately address gender and cultural biases in themselves, in others, and in the health care delivery process" (LCME 2016). This includes instruction regarding issues such as cultural diversity in conceptualization of health and illness, the basic principles of culturally competent health care, and the importance of meeting the health care needs of medically underserved populations. The Association of American Medical Colleges identified five domains for cultural competency, including key aspects of cultural diversity in healthcare, impact of stereotyping on medical decision-making, health disparities, and cross-cultural clinical skills. It also developed a 67-item Tool for Assessing Cultural Competence Training (TACCT) to help medical schools assess and identify gaps in their cultural competence training (AAMC 2006). And, the National Standards on Culturally and Linguistically Appropriate Services(CLAS) have been increasingly implemented through state- and CLAS-sponsored activities (U.S. Department of Health and Human Services n.d.). These Standards call for "respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs." (Office of Minority Health: U.S. Department of Health and Human Services 2013)

In health research, including PMR, cultural competency trainings are similarly aimed at improving researchers' understanding of diverse health-related belief systems and enabling them to better engage with (primarily) racial/ethnic communities throughout the research [(George et al. 2014)]. Cultural competency is also viewed as a tool for building rapport and increasing trust between researchers and participants, not least through the expectations that researchers adopt culturally and linguistically sensitive measures to conduct their studies (National Institutes of Health 2017). These measures include offering non-English (especially Spanish) material about the research and collaborating with racial/ethnic communities to develop research objectives, design, material, and interactions that are responsive to the needs, priorities, and interests of the respective communities (George et al. 2014; Banks et al. 2013).

Moreover, following in the footsteps of healthcare settings (Office of Minority Health: U.S. Department of Health and Human Services 2013), cultural competency trainings in PMR are increasingly viewed as necessary measures for demonstrating an organizational commitment to engagement and accountability, and, indeed, as a sine qua non of the protection of the rights and welfare of human research subjects across

cultures. Currently, many of these efforts have focused on indigenous people. Historical misuses of genomic data obtained from indigenous communities have called attention to the need for cultural sensitivity, and both scholars and tribal communities began drafting guidelines for culturally sensitive engagement in genomic research, including PMR (Claw et al. 2018). Yet, the NIH-funded All of Us Research Program has taken the need for cultural competency a step further. This national program endeavors to establish a 1-million cohort of volunteers who will provide biological, environmental and lifestyle data for PMR. Participants will also play a long-term and active role in data collection and study design, all with the aim to accelerate PMR and to "usher in a new and more effective era of American healthcare." (The Precision Medicine Initiative Working Group 2015). Unlike previous NIH guidelines that only urged researchers to develop appropriate and culturally sensitive outreach programs (National Institutes of Health 2017), the All of Us Research Program has explicitly recognized that enrollment and retention of participants entails respectful and culturally appropriate engagement with them (The Precision Medicine Initiative Working Group 2015; NIH 2018; Khodyakov et al. 2018). Accordingly, its Institutional Review Board (IRB) requires that collaborating sites demonstrate that their staff, at all levels, have cultural competency to engage with all potential and enrolled research participants (All of Us Research program institution specific IRB application (ISIA) n.d.). This stipulation, which is not limited to any specific community, further requires information as to how collaborating sites (i.e., lead investigators) will implement this requirement with respect to other members of their research teams (e.g., research coordinators, nurses, genetic counselors; hereafter precision medicine (PM) personnel).

To date, little attention has been given to the need for increasing the knowledge of PM researchers and personnel about disability rights, history, and needs (hereinafter disability culture competency). However, there are good reasons to question this omission. Twenty-two percent of US adults are reported to have disabilities, broadly defined in the US Census and in the Convention on the Rights of Persons with Disabilities to include those with long-term physical, mental/psychosocial, intellectual, and sensory/communicative disabilities (Courtney-Long et al. 2015). As a group, people with disabilities also comprise the largest health disparity group in the USA (Krahn et al. 2015; The secretary's advisory committee on national health promotion and disease prevention objectives for 2020 n.d.). Although some people with disabilities may have increased medical needs due to their primary disability, studies consistently show that both patients and healthy people with disabilities are more likely to receive lower quality and less comprehensive health services, including fewer screening and preventative services than people without disabilities (Krahn et al. 2015; Wisdom et al. 2010). Additionally, research

indicates that the prevalence of disability, of deficiencies in healthcare delivery, and of the subsequent disproportionately high incidence of health disparities, is higher among people with disabilities from racial/ethnic communities, especially African-Americans, Latinos, and American Indians/Alaska natives (Goode et al. 2014). Including people with disabilities in PMR is therefore necessary to advance the scientific goals of PMR, to promote health equity and population health, and to uphold the equal right of persons with disabilities to enjoy the potential benefits of PMR (Sabatello 2017).

Comprehensive data about participation of people with disabilities in PMR are not available. However, there are reasons to believe that, without appropriate strategies in place, persons with disabilities will not be well represented in PMR (similar to most mainstream health research (Rios et al. 2016)). Studies suggest that participation of persons with disabilities in research is limited due to use of comorbidities as exclusion criteria in clinical trials (Sarfati et al. 2016) and overly protective IRBs, which increase the risk of non-inclusive decisions on research participation (Iacono 2006). Most many may attribute this outcome to individuals' inabilities to participate because of their specific conditions (e.g., questions surrounding the competency of people with intellectual and psychiatric conditions to consent to research participation). However, research in healthcare settings suggests that a lack of disability-relevant knowledge about accessibility and other sociocultural barriers (e.g., unconscious bias) may also play an important role in this underrepresentation in research (Duggan et al. 2011; Mudrick et al. 2012; Sneed et al. 2000; Sanborn and Patterson 2014).

These findings should be taken seriously by PMR enterprises. Many PM researchers and personnel are educated in medical schools and other genomic-based programs (e.g., genetic counseling, molecular biology, and genetics). Yet, unlike other cultural competency expectations (see above), disability competency is not a core curriculum requirement for accreditation or receipt of federal funding (National Council on Disability 2009). Disability competency trainings in medical schools in particular (though also in other genomic-based programs) are subsequently limited (Duggan et al. 2011; Sneed et al. 2000; Sanborn and Patterson 2014; Madeo et al. 2011). This lack of disability education may unintentionally lead to non-inclusive decisions by PMR personnel and IRB members that hinder the participation of people with disabilities in PMR.

Further complicating the matter is that some PM researchers are also healthcare providers. Indeed, one of the major consequences of the rise of translational genomics research—the effort to integrate genome-scale sequencing, including PMR findings into clinical care—is that clinicians increasingly participate in the design of genomic and PM studies, while simultaneously delivering care to research participants (Wolf et al. 2018). Yet, this situation of PM researchers serving as PM clinicians (and vice versa) may also

impact disability inclusion in PMR. First, it raises the possibility that limited knowledge about and understanding of disability-relevant issues that occur in health clinics will to extend to PMR settings, and, as discussed below, discourage participation in PMR. Second, it raises the possibility that issues of mistrust that people with disabilities experience in clinical settings (National Council on Disability 2009) will extend to PMR (as has been shown to occur among racial/ethnic groups (Kraft et al. 2017)).

This article explores the need for disability culture competency in PMR. It highlights the challenges that people with disabilities are likely to experience should they be interested in participating in PMR, moving from issues relating to disability accessibility and accommodation to the impact of societal attitudes, language and communication. Given the lack of data on the experiences of people with disabilities in PMR, the article draws on other comparable sources to probe the challenges for inclusion. These include studies in healthcare settings, which are major sites of contemporary translational genomics research, research about participation of people from other historically marginalized communities in genomic research, and other scholarship relating to the participation of people with disabilities in health research. Because the stakes are high— i.e., benefits of PMR are unlikely to accrue to those who are not included in research—the article calls for rethinking of the reasons that may exclude the participation of people with disabilities in PMR. Specifically, it views the traditional (and predominant) focus on how to obtain consent or assent from people with disabilities as important, yet insufficient component for respectful engagement with and long-term retention of research participants. Instead, the article highlights the responsibility of PMR researchers, staff, and members of IRBs to be better informed about the needs and cultural nuances of the disability community (on its heterogeneity, as discussed below); more reflective about their own biases about disabilities; and more thoughtful in their research strategies about securing disability accessibility, accommodation, and participation throughout the study. Towards this goal, the article finally offers some initial thoughts about what such disability culture competency trainings may entail and provides a conclusion.

Disability rights, history and needs

The history of disability rights encompasses almost four decades of national and international activism and several waves of efforts to construct and re-construct disability as a social, political, and cultural phenomenon (Sabatello 2014). As in other civil rights movements in the USA, such as the women's rights movement, constructs of disability have evolved over time and vary in their emphases on disability as an individual, collective, and pluralistic experience (Shakespeare 2014). However, waves of the disability rights movement share a

critical perspective on the medical model of disability, which tends to view disabilities as personal traits in need of curing, and a contestation of both the conventional equation of disability with sickness and disease and the depiction of disability as a life of misery. As disability advocates have emphasized, such conceptualizations of disability may reflect neither reality (e.g., one can have a disability but be healthy) nor the enjoyment of life as experienced by many people with disabilities (Shakespeare 2014). Instead, disability advocates and scholars have long accentuated the societal, attitudinal, and institutional barriers to participation in society; the importance of refocusing attention on abilities and supports; and the need for appreciation of the lived experiences of people with disabilities. Rather than the prevalent positioning of people with disabilities as objects of charity, disability advocates and scholars call for inclusion, citizenship rights, and recognition of their agency.

It is also from this vantage point that the value of people with disabilities being involved in PMR conversations must be considered. Although there is no civil duty to enroll in biomedical research, PMR has evoked a growing discourse about the rise of genomic citizenship, encompassing certain rights and responsibilities, not least because of the notable governmental support and encouragement for such involvement (Sabatello and Appelbaum 2017). Even if one is skeptical (or concerned) about the implications of these developments, a core issue at stake is the equal opportunity (pending one's decision) to be part of these processes. As a study of people with intellectual disabilities found, the benefits of participation in research far exceed the potential scientific and health benefits of research; they encompass issues such as empowerment, increased self-esteem, and a sense of equality, contribution, motivation, and belonging (McDonald et al. 2015). Insofar as members of the disability community choose to participate in PMR, they should be enabled to do so, similar to other members of society.

Some may question whether people with disabilities qualify as a "community." Given that "disability" as a category is immensely heterogeneous and that people with similar disabilities may have different health needs, the conceptualization of people with disabilities as a collective similar to other racial/ethnic communities, e.g., African-Americans, may seem odd. Such a community, it may be argued, lacks a distinctive shared history, culture and tradition—features that usually characterize racial/ethnic groups. Further complicating the matter is the lack of a cross-cultural definition of disability. Although disability is a universal phenomenon—cutting across age, gender, and racial/ethnic groups—causes, explanations, and categorizations of disability vary significantly and depend on societal perceptions of "normalcy" and on one's religious, ethnic, social, and cultural backgrounds (Sabatello 2014). PM researchers and institutions may thus believe that existing racial/ethnic- and linguistic-based cultural competence trainings already encompass the

necessary knowledge to properly encounter diverse populations, including people with disabilities.

In health research, disability may also seem incongruent with the conventional construct of a community warranting protection. The latter is often understood to mean one in which individuals are at increased risk for harms because of their actual or perceived membership in the group and/or that the group is sufficiently structured to be harmed in and of itself if cautionary measures are not implemented ("group harms") (Hausman 2007). This construct of a community warranting protection raises unique issues for the disability community.

On the one hand, the history of genomic research and the rise of the eugenics movement in the twentieth century cannot be disconnected from the history of disability. The Nazi's extensive euthanasia program and use of body parts of those killed for research began with a child whose father pleaded with Hitler to kill due to his disabilities (Hudson 2011). Ascription as members of the disability community served as a justification for conducting brutal experimentations on people with disabilities in Auschwitz and in medical settings, especially mental health institutions throughout the Third Reich (Barondess 1996). Subsequent abuses of children with disabilities in research (e.g., Willowbrook State School) and ongoing efforts in the USA and elsewhere to "purify" the genetic pool of the human race from those classified as "feebleminded" "imbeciles," or with anti-social behavior (Allen 2001) further highlight the vulnerability of this population in the hands of science. On the other hand, not all people with disabilities affiliate themselves with the disability community or the disability rights movement (Shakespeare 2014), and, with some exceptions (e.g., the Deaf community), the organizational structure of the disability community is often more casual than other groups that have experienced group-level harm (e.g., the Havasupai tribe).

However, differences within sociocultural and biomedical groups, including disagreements about individual affiliation and identity, are an inherent part of human diversity (King 1992). Moreover, as has been long documented and acknowledged in national and international laws, including the Americans with Disabilities Act (ADA), experiences of exclusion and discrimination are commonly shared among and across subgroups of people with disabilities. Thus, although disability heterogeneity may often require taking an disability-specific approach (Shakespeare 2014), the relevance of these shared experiences for healthcare, health disparities, and health research, including PMR, also necessitates a group-level address.

Barriers to disability inclusivity in PMR

The conceptualization of people with disabilities as a community with unique interests and group-level experiences has

significant implications for PMR. Here, I consider three inter-related key disability culture competency issues that are likely to impact disability inclusivity in PMR.

Disability accessibility and accommodation

The need for disability accessibility and accommodation in healthcare settings is well-known in the literature. Such services are required in US and international laws, including the ADA, its guidelines and the Affordable Care Act; their absence is well-established as a leading cause for poorer health outcomes in this population (Goode et al. 2014).

Nonetheless, studies consistently show that many healthcare facilities and equipment are inaccessible for persons with disabilities (Krahn et al. 2015; Sharby et al. 2015). Beyond structural issues (e.g., stairs rather than ramps), studies indicate that healthcare providers and administrators have limited knowledge about accessibility and accommodation. A study of general, family, internal, and OB-GYN practice clinics, for example, found that the majority of primary care practice administrators were neither aware of the ADA's list of accessible equipment (e.g., height-adjustable exam tables) nor what accessible equipment exists, even though administrators are typically the ones to have oversight of facility operations, equipment purchasing, and patient flow (Pharr 2013a). Studies further indicate that clinicians' understanding of communicational accommodations for subgroups of people with disabilities are especially limited. For instance, although many Deaf individuals use sign language as their primary language, certified interpreters are infrequently available, an outcome that has been attributed to physicians' lack of awareness of their legal obligation to provide an interpreter (Hoang et al. 2011), a misunderstanding that alternatives (e.g., lip reading, written information) are inadequate (Steinberg et al. 2006), and a common assumption that one type of auxiliary aid "fits" the needs of an entire disability subgroup (which in reality, may not provide individual-level accommodations) (Withers and Speight 2017).

Inadequate understanding of disability accessibility and accommodation among PM researchers and personnel may discourage the participation of patients and healthy people with disabilities in PMR. For example, information that is not available in disability-accessible formats increases the possibility that persons with disabilities may not learn about PMR opportunities (Sabatello 2017). Inaccessible information also increases the possibility that research participants who become disabled after enrollment—which, across lifespan, the latter group potentially includes most if not all of us (Garland-Thomson 2017)—will drop out as environments and information become inaccessible to them. Insufficient knowledge about how to design PM studies that are accessible to people with a range of abilities ("universal design") and that offer accommodations may also lead to incorrect presumptions about inabilities to participate (e.g., that blind people cannot complete a questionnaire) and result in unjustified exclusionary decisions as well as non-generalizable research findings (Rios et al. 2016; Williams and Moore 2011).

Conversely, educating PM researchers about relevant disability laws and their obligations thereof, raising awareness about assistive devices and technologies, and incorporating disability-accessible measures at the outset of PMR programs may have a positive effect. These may include, for example, providing informed consent and survey in braille or developing videos of study material in American sign language, steps that can facilitate inclusion of and comprehension among blind and d/Deaf participants (Singleton et al. 2014). Following the Web Content Accessibility Guidelines (WCAG) 2.1 would enable programming online study material that is accessible for participants with a range of vision, cognitive, and mobility abilities (Web Accessibility Initiative (WAI) - the World Wide Web Consortium (W3C) 2018). Such measures would further reduce the need for later adaptation for certain populations (steps that, in the meantime, exclude participation) and increase the likelihood of participation in PMR and, thus, of finding meaningful genomic and other results. In the long term, access to ensuing benefits of PMR could also reduce health disparities and costs associated with poor health outcomes.

Disability stigma and unconscious bias

Notwithstanding changes that have occurred since the adoption of the ADA, cultural representations of disability have historically been negative (Shakespeare 1994). As studies consistently show, people with disabilities have often been viewed as helpless and object-like; their classification as "defective" and "abnormal" has commonly evoked devaluation, fear, and the desire for social distance (Shakespeare 2014).

As other members of society, it is possible that stigma and unconscious bias about disabilities exist also among healthcare providers (Duggan et al. 2011; McColl et al. 2008). For example, research with healthcare providers found that many consider interactions with persons with disabilities, especially those with mental/psychosocial disabilities, to be more time-consuming and emotionally draining (McColl et al. 2008; Stuart et al. 2015). Studies further indicate that many healthcare providers express discomfort treating and communicating with patients with disabilities about their disabilities, especially when other general and preventative health needs arise (Smith 2009; Wilkinson et al. 2012). As scholars have thus observed, disability may become the "elephant in the room": physicians may ignore it, even when relevant, or overly react to it when irrelevant (Duggan et al. 2011; McColl et al. 2008). Both attitudes may contribute to the health disparities experienced by people with disabilities,

notwithstanding health professionals' general medical expertise.

Similarly, the prevalent presumption that persons with disabilities are incompetent may strain provider–patient interactions (de Vries McClintock et al. 2016). For instance, studies found that persons with disabilities oftentimes feel that—regardless of their disability type—their views in healthcare settings are not sought or listened to, and that even when they engage in the conversation, physicians tend to respond to their caretakers (Smith 2009). One study further reported that, due to presumptions of inabilities, practice administrators often request people with disabilities to be accompanied by others for medical appointments, even though this practice contravenes with the ADA (Pharr 2013b). Thus, even when receiving high-quality medical care, people with disabilities may feel that they are disrespected, invisible, and "treated as a disease or a body part" (de Vries McClintock et al. 2016).

In PMR, disability stigma and unconscious bias may result in two types of exclusion. The first is intellectual exclusion from knowledge production. Among the innovative features of contemporary PMR enterprises, including the All of Us Research Program, is the emphasis on participants' empowerment and participation (The Precision Medicine Initiative Working Group 2015). Under this vision, research participants are viewed as partners and active contributors to the development of scientific knowledge. However, if disability narratives and experiences are not appreciated, there is a risk that insights, expertise, and life experiences of persons with disabilities will be silenced or undervalued. As members of the neurodiversity community have expressed, e.g., research on autism often imposes normalizing narratives for autism-related behaviors, without exploring their meaning and significance for the participants themselves (Milton 2014; Milton and Bracher 2013). Notwithstanding disagreements within and outside the disability community (broadly defined) about definitions of disability, and whether and which conditions should be treated (Scully 2008), awareness of these issues is important. If disability culture and experiences are not appreciated, the study of environmental and lifestyle factors—the two other key components of PMR, beyond genomics—that impact health interventions and outcomes will be inherently limited. Such a lack of disability appreciation further increases the risk for discrimination in PMR. While participants with disabilities will contribute biological data, they will be viewed only as disembodied datasets and excluded from the panoply of participants' knowledge production that PMR embraces (Sabatello and Appelbaum 2017).

As has occurred in other health research (Rios et al. 2016; National Council on Disability 2009; Agency for Healthcare Research and Quality 2010), misconceptions about disabilities may further lead to a second type of exclusion, i.e., that people with disabilities will be precluded from participating in PMR. Such exclusion may encompass people with a range of disabilities, and may arise because of the common perceptions of incompetence (see above) (de Vries McClintock et al. 2016), or due to the researchers' perspectives of disabilities only as end points in studies rather than as demographic characteristics of participants (Williams and Moore 2011). The ramifications of physical exclusion are particularly concerning for PMR, the bedrock for PM as the next generation model of healthcare. Without sufficiently powered cohorts of people with a variety of disabilities, identifying meaningful findings, developing tailored care for such individuals, and reducing rather than exacerbating health disparities will be unlikely.

The risk of intellectual and physical exclusions is especially pronounced for people with intellectual or mental/psychosocial disabilities. Because such impairments may impact decision-making capacity, the tendency to presume incompetence at a group level may be applied regardless of the actual abilities of the individual (Ganzini et al. 2005; Werner et al. 2017). Some persons with disabilities may also have guardians or proxies involved in their healthcare decisions, whose presence may hinder PMR's inclusivity, even if unintentionally. Indeed, although guardianship originated to safeguard the interests of individuals deemed incompetent in certain areas of decision-making and was intended to apply for the limited time of their incompetence, studies indicate that physicians and researchers often interpret it to mean a permanent lack of ability to make any decision (Ganzini et al. 2005). People with intellectual and mental/psychosocial conditions are thus commonly subjected to the decision-making of their guardian, often with little to no input of their own, or excluded from participation entirely (Iacono 2006; Williams and Moore 2011). Although these approaches aim to provide protection, their pervasive use also perpetuates the perception of such individuals as object-like rather than as subjects capable of participation.

Disability culture competency is unlikely to, and should not necessarily, translate into a requirement to abolish all guardianship arrangements, some of which encompass more contemporary models of supported decision-making (Kohn et al. 2013). Nor should it be viewed as agnostic about the existence of impairments and their possible impact on the experiences and opportunities one may have. However, disability culture competency could increase PMR inclusivity by increasing disability knowledge among PM researchers and personnel, which studies in healthcare settings have demonstrated to improve physicians' attitudes towards their patients with disabilities (Werner et al. 2017). It would also highlight the need for re-focusing on individuals' abilities: interrogating how people with intellectual and mental/psychosocial disabilities can engage in studies or what sort of supports they may need for decision-making (Ganzini et al. 2005; Kohn et al. 2013) (e.g., developing study material in plain language). It would further accentuate PM researchers' obligation to ensure that periodic, interdisciplinary re-evaluations of capacity and formal processes for participants' engagement and, at least,

assent are in place. And, it would underscore the responsibility of PMR oversight committees to monitor the implementation of these processes and, indeed, to ensure that conversations about protection of human subjects are reframed to encompass disability rights and inclusion.

Disability language

Words are powerful. They can empower or disenfranchise, convey messages about "deviancy" (however defined), and shape our mental and social worlds. Thus, language has played an important role in the American and international disability rights movements. For example, in the USA, person-first language is generally preferred: it recognizes an individual's abilities by placing the person, as a subject, before a disabling identifier, i.e., "persons with disabilities" rather than "disabled person." (Some sub-groups do prefer identity-first terminology; see below.) Many self-advocates with psychiatric conditions favor "psychosocial disability" over "mental illness/disorder" (World Network of Users and Survivors of Psychiatry 2008). Whereas the former acknowledges experiences and sociocultural participation restrictions related to mental health conditions, the latter centers on medical taxonomy (Pallickal Jose et al. 2016).

Emerging studies further indicate that many people with disabilities find adjectives to describe disabilities (e.g., "crippled," "insane," and "retarded" or the "R-word" in disability studies), group designations (e.g., "the disabled"), and expressions of tragedy (e.g., "stricken," "afflicted, "wheelchair bound," and "handicap," which, by some accounts, originated from hand-in-cap, i.e., a beggar) to be offensive (West et al. 2015). In this regard, many within the disability community view such language as failing to represent their full life experiences and individuality, and worse: that it may be harmful in its stigmatizing messaging and reinforcement of stereotypical perceptions of persons with disabilities as passive and inadequate actors, less valuable members of society. Indeed, for some people with disabilities, inappropriate disability language reflects a culture of disablism or ableism, i.e., the systematic and institutional devaluing of bodies and minds deemed defective, an ideology that—similar to racism and sexism—discriminates against people based on their bodily characteristics (Shakespeare 2014).

In PMR, as elsewhere, respect for human subjects begin with language. Yet, studies indicate that healthcare professionals tend to use medical/impairment-focused phraseology and expressions of pity (or on the contrary, of exaggerated heroism) in communication with persons with disabilities (Duggan et al. 2011; Sanborn and Patterson 2014). Although such practices are not intended to disrespect people with disabilities, studies suggest that such interactions may lead to distrust and reduce the likelihood of patients' interest in further engagement (Duggan et al. 2011). These findings may have particular ramifications for the success of disability inclusivity in PMR. First, insofar as patients' decisions to enroll in PMR are positively impacted by the trust relationship they have with their physicians (Kraft et al. 2017), patients with disabilities may decline to participate even when they are invited to do so (Sabatello 2017). Second, without appropriate disability education, it is possible that PM researchers and personnel will similarly utilize misguided disability language, thus increasing the risk that these aforementioned consequences of distrust will occur in PMR settings. Finally, research on racial/ethnic communities and trust in PMR may be instructive: it found that local dialects, cultural nuances, and recognition of historical experiences of abuse are key components for trust-building efforts in PMR (Kraft et al. 2017).

Educating PM researchers and personnel about the historical transformations of disability language could therefore be a first step in the right direction. It would highlight the importance of communicating with people with disabilities no different than with people without disabilities. It would demonstrate sensitivity to the cultural significance of disability rhetoric and respect for persons with disabilities as equally valued subjects in society. It would acknowledge the historical wrongs that were enabled by using derogatory language to separate the "fit" from the "unfit" (consider, e.g., the label of "feebleminded" in the eugenics and Nazi eras). It may also help in reversing the experience of institutional disablement, thus providing the opportunity for trust relationships to be established.

The need for disability-appropriate language and linguistic nuances are not without controversy; indeed, even the person-first language is not agreed upon across disability communities. The National Federation of the Blind, e.g., has long deplored the insistence on person-first language as being "overly defensive, [implying] shame instead of true equality" (Jernigan 2009). Other self-advocates prefer identity-first language, highlighting that their condition cannot be disassociated from themselves. Members of the Deaf community, e.g., do not view their deafness as a disability but as a cultural and linguistic uniqueness; the capital D identifier (rather than small d) accentuates their deaf identity and their identification as culturally deaf (Steinberg et al. 2006). Similarly, some members of the autism and neurodiversity communities self-identify as "Autistic" or "Autistic person/individual": they view autism as a cognitive/communication difference (not deficit) and an inherent part of their identities, no different than other groups that accentuate certain aspects of their being, e.g., African-Americans [(Brown n.d.)].

These issues are important and call for caution. Disability language needs to be respectful of the preferences of the subjects involved, while concurrently recognizing that disagreements about language among disability groups or individuals with disabilities are likely to persist. One possible measure to address this issue is if PM researchers and personnel discuss

with potential participants their views and learn about the preferred language of relevant disability communities before reaching out to them. Indeed, in this regard, disability culture competency is not—and should not be construed to mean—an effort to impose certain terminology or a mere exercise in political correctness. Rather, the importance of knowledge about disability language lies in the values underlying it: the acquaintance of PM researchers and personnel with the history of disabilities as sociocultural phenomena, the attention to how seemingly well-intended communication may go awry, and the potential for these understandings to help in developing—in combination with other educational components discussed above—greater openness to disability conversations between PM researchers or personnel and people with disabilities as subjects of PMR.

PMR and disability culture competency trainings

Scholarship on disability culture competency is sparse (Garland-Thomson 2017), and, with the exception of NIH guidelines on cultural and linguistic competency in heath research with Deaf sign language users (National Institutes of Health 2016), existing work has focused on healthcare (not research) settings. However, recent initiatives are suggestive of the possible impact that disability culture competency trainings may have for inclusivity in PMR.

To date, a variety of programs have been developed to increase disability awareness among healthcare providers. These include instructional presentations delivered by faculty, staff, and people with disabilities (Duggan et al. 2009); supervised encounters with patients or advocates with disabilities; experiential training through clinical work or placement with community facilities for and organizations of people with disabilities (Anderson et al. 2010); and an array of continuing education opportunities, such as interdisciplinary training workshops (Shakespeare and Kleine 2013). The level of success of these interventions varies, and as a practical matter, comparisons are complicated, given the diversity of disability trainings and a lack of standardized requirements for them (Sanborn and Patterson 2014). However, a comprehensive review of these interventions found significant improvement in knowledge across programs, with those programs that were longer in time, that included in-person meetings with people with disabilities, and that required program-participants to critically reflect on their experiences proving to be most valued by professionals (Shakespeare and Kleine 2013).

Which of these interventions—given time, resources, and personnel constraints—may work best for PM researchers and personnel and for the success of PMR enterprises is unknown. As with other cultural competency trainings (Govere and Govere 2016), there is a further need to evaluate whether such

trainings indeed improve research participants' satisfaction and health outcomes. However, as a starting point, it seems key for disability culture competency trainings to build on the findings of these earlier studies and to address the three interrelated barriers discussed above—i.e., disability accessibility and accommodation; disability stigma and unconscious bias; and disability language and communication—all of which may have direct impact on trust and inclusion in PMR.

Significantly, these measures are not intended to provide a comprehensive framework for engaging people with various abilities in PMR. Nor do they aim to create a new concept of cultural competency. On the contrary, they aim to augment existing pillars of cultural competency trainings. As mentioned earlier with regard to historically marginalized racial/ethnic communities, cultural competency trainings in health and research settings aim to increase professionals' substantive knowledge of different health cultures and beliefs, to facilitate exchange of information, and to develop self-awareness of biases, including through direct interaction with individuals from varied cultural communities. Accordingly, all these measures should remain part and parcel of disability cultural competency trainings, while the issues and barriers discussed in this article provide moregranular specificity to achieving these goals, including the need for cultural humility (Isaacson 2014).

It will be necessary for PM researchers to work with interdisciplinary teams alongside disability experts to develop this material. Ideally, such collaborations would include disability scholars, PMR researchers, and healthcare professionals, including specifically those with disabilities, and members of the disability community more generally. Such an approach would comport with the commitment of PMR to community-based research and engagement, and it would recognize the expertise of people with disabilities. It would also take seriously the need for understanding intersecting health values, histories, needs, and identities among people with disabilities that may impact enrollment decisions. For instance, perceptions of disabilities may vary across racial/ethnic groups, and barriers in accessing health research, including PMR, may be compounded for people with disabilities from racial/ethnic minorities (Onyeabor 2016). Understanding intersectionality within the disability community—i.e., the experience of disability as a demographic interacting with race, class, and gender as well as a consequence of subordination and discrimination (Ribert 2010)—is key for inclusion. Thus, without negating medical and scientific knowledge and progress, disability culture competency trainings should be viewed as a way to focus attention among PM researchers, personnel, and institutions on the social, cultural, and political structures that affect health outcomes among disability subgroups and the larger disability community, and the roles thereof for ensuring disability inclusion through connections, accessibility and accommodation.

IRBs too have an important role in ensuring disability inclusivity in PMR. As the gatekeepers of the ethical and legal landscape of research with human subjects, their decisions about research participation are key. Without an understanding of disability rights, history, and needs, there is a risk that IRBs' concerns about protection of participants with disabilities will be overly restrictive and unjustifiably exclusionary (Iacono 2006). Furthermore, because inadequate disability knowledge may lead, without bad intentions, to disrespectful and discriminatory practices towards participants with disabilities, IRBs have the responsibility to ensure that PM researchers and personnel undergo disability culture competency trainings and that they refresh and continue their disability education throughout their research. This approach would reinforce long-term learning and reduce the risk that the newly gained knowledge will diminish over time (Shakespeare and Kleine 2013). Even if, as with other cultural competency trainings, IRBs may not single out a specific disability competency training over another, they could monitor whether such trainings are developed and implemented through sensitive engagement with relevant disability communities. Such monitoring would protect the welfare and rights of participants with disabilities, and offer the initial trust-building measures that are imperative for inclusivity in PMR.

Conclusion

Disability education among PM researchers, personnel, and IRB members is key for cultivating inclusivity in PMR. With a proliferation of PM studies across the country, including the creation of the national All of Us Research Program, there is a unique a unique opportunity to address the issue of disability culture competency, and indeed, to transform existing research (and healthcare) infrastructures and attitudes to address the challenge of health disparities in the USA. For all people, including those with current and future disabilities to enjoy the potential benefits of PMR, it will be necessary to shift the conversation by ensuring that PM researchers, personnel, and institutions are aware of disability rights, history, and needs, and by developing research practices for PMR that are inclusive and respectful of human subjects, regardless of their (dis)abilities.

Compliance with ethical standards

Conflict of interest The author declares that she has no conflict of interest.

Ethical approval This article does not contain any studies with human participants or animals performed by any of the authors.

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